

In back alleys near Vancouver's AIDS conference, the disease was gaining ground

Richard Cairney

In Brief • En bref

There was much more to this summer's international AIDS conference in Vancouver than reports by researchers. Richard Cairney says the \$15-million conference attracted a mix of activists, demonstrators, physicians and business representatives, and they coexisted somewhat uneasily.

La Conférence internationale sur le SIDA qui s'est tenue cet été à Vancouver n'a pas été limitée à des rapports de chercheurs. Richard Cairney déclare que la conférence de 15 millions de dollars a attiré des militants, des manifestants, des médecins et des représentants d'entreprises, qui ont tous coexisté avec un peu de difficulté.

Having no frame of reference for correct behaviour in the midst of an epidemic that has taken millions of lives and threatens millions more, it was predictable that the international conference on AIDS held in Vancouver this summer would take place under a bitter pall of death and anxiety. Stuck between the suburbs and the sea, researchers, activists and the living dead — those with full-blown AIDS or infected with HIV — got along as best they could, given the tragic circumstances drawing them together.

For a week, the XI International Conference on AIDS featured announcements of apparently miraculous treatments punctuated by angst-filled screams of activists determined not to die without a fight.

Meanwhile, a few blocks away from the Vancouver Trade and Convention Centre, where some of the world's brightest researchers discussed viral-load testing, chemokine receptors and protease inhibitors, the disease was gaining ground.

The intersection of East Hastings and Main streets may be the epicentre of HIV transmission in Vancouver. This is an area where people pay good money to become infected with HIV, because this virus is fuelled by addiction and libido. In an alley across the road from a Main Street police station, drug addicts share needles. Prostitutes will, when their customers insist, have unprotected sex. Gloria Powder, an AIDS educator with the British Columbia First Nations AIDS Society, says both behaviours occur with alarming frequency.

A former drug addict and prostitute who worked in the Hastings and Main area, Powder now peddles

a message of prevention to hookers and junkies whose knowledge of the disease is often derived from urban legends and myths.

"They ask about kissing and blow jobs and stuff like that, and about open cuts, tears, sweat," said Powder. "They know about needle sharing but they are confused about unprotected sex."

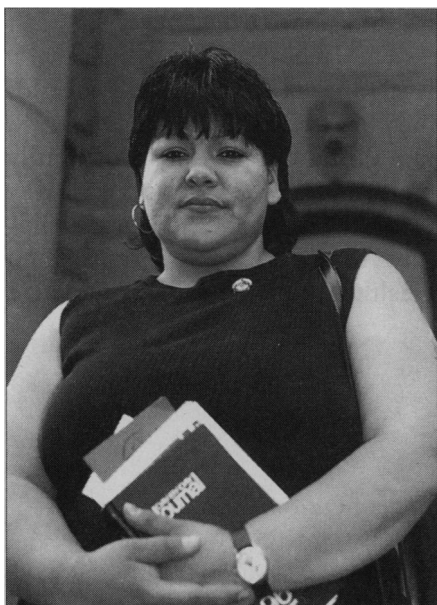
"When I first came to Vancouver 6 or 7 years ago, I was living here [East Hastings], working the street to survive. I've shared needles — I won't deny that. I had heard about HIV, but I thought it was a gay disease."

It is precisely this street setting that demands immediate attention, Powder argued. She didn't expect that Vancouver's \$15-million AIDS conference, which was expected to generate \$31 million in spending, would be of any use to her or the people she is trying to save.

"You have to find a cure, sure, but the number-one job is awareness and prevention," said Powder, whose sister died working Vancouver's streets. "First Nations people are not aware of this virus. If [people] get HIV in our communities they are outcast and they have to come out here to die, with no family. Their ashes are left in the morgue because no one will come and claim them — the elders think they can get something from the ashes. In the past month, I've had a lot of people die. It makes you angry sometimes."

Richard Cairney is a reporter and editor with the St. Albert Gazette in Alberta.

© 1996 Richard Cairney



Gloria Powder: "You have to find a cure, sure, but the number-one job is awareness and prevention."

No one expressed their anger more clearly than members of Act Up San Francisco, a renegade chapter of the international group Act Up (AIDS Coalition To Unleash Power). Members of the San Francisco chapter are considered outlaws because they say the integrity of established Act Up chapters has been compromised by drug-company funding. Following nonmainstream theories of HIV/AIDS and its treatment, chapter members staged a "dissenters' forum" to denounce the "McAIDS" industry.

Calling Act Up a "bulldog" for pharmaceutical companies, Act Up San Francisco member Michael Bellefountain, an AIDS patient, said he thinks activists have been seduced by drug companies. "We feel we are salvaging Act Up's name," he said.

Bellefountain, who claimed a degree of success in hampering cooperation between gay-activist groups and drug companies, said the group is setting its sights on a moving target. "The queer community has stopped enrolling [in drug trials]," he told a small audience attending the one-night dissenters' forum. "Now there are campaigns to recruit single moms."

Members of the San Francisco chapter, who call themselves social enzymes, were arrested on the eve of the conference's close after activists stormed a symposium sponsored by Glaxo-Wellcome. The renegade members stormed the head table and poured stage blood on researchers.

Other Act Up chapters disavowed any association with the group, with some theorizing that its members need "a monster" to blame and fight. "They're crazy," said an Act Up Golden Gate member. "They don't believe HIV causes AIDS. One of the guys who came in with our group was physically attacked [for being associated with someone taking a new drug]. Somebody from Act Up San Francisco beat him after he told the guy his lover had just started taking one of the protease inhibitors."

Canadian protesters acted up in their own way, turning their backs, plugging their ears and blowing whistles when federal Health Minister David Dingwall spoke during the conference's opening ceremonies. Bluma Appel, chair of the Canadian Foundation for AIDS Research (CANFAR), was incensed by the

shenanigans. If protesters really wanted to put on a show, she fumed, they should have paraded AIDS patients in wheelchairs having blood transfusions around the stage's footlights.

Maggie Atkinson, an AIDS patient, a founder of Voices of Positive Women, cochair of AIDS Action Now! and a member of the Canadian AIDS Society, said AIDS patients must do something to have the federal AIDS strategy and its funding renewed.

"If we just sit back they're going to discontinue the funding and we're going to die. And people say to me, 'Well, isn't it rude to turn your back on the health minister?' Well, [if] you see the health minister isn't going to help people with AIDS, who are literally dying every day, how rude is that? He has to be held accountable and so does [Prime Minister] Jean Chrétien. Even Mulroney was man enough to come to the Montreal International AIDS Conference — Chrétien has been a coward [for refusing to attend]."

Atkinson came to the conference to find out which protease inhibitor she should take and to lobby for new federal funding for AIDS research



AIDS activists storm Health Canada booth during Vancouver conference. They were protesting Prime Minister Chrétien's absence and government inaction.

and education programs. A well-educated woman of 34, Atkinson appeared in the conference line-up's distinguished-lecturer series. She is a valuable weapon in the activists' arsenal. Smart, navy-blue power suits differentiate her from her more apocalyptic colleagues. Speaking eloquently and demonstrating media

savvy, she knows personal questions come at the end of an interview.

"I'm 34, I was infected in 1984, my partner died in 1992," she said, pre-empting an awkward moment. Offered sympathies over the death of a loved one, Atkinson seemed taken aback. "Well," she responded in an almost indignant, matter-of-

fact tone, "we're dying every day."

The lack of action at the federal level also tainted the conference for members of the medical community. Dr. Philip Berger, head of family medicine at Toronto's Wellesley Central Hospital, showed his support for protesters who stormed Health Canada's exhibit booths. He

BUSINESS WARNED OF AIDS' FAR-REACHING ECONOMIC COSTS

Data from Ottawa's Laboratory Centre for Disease Control show there may be up to 20 000 AIDS patients in Canada today, although the number of reported cases stood at only 13 810 on June 30. The cost of treating each patient is approximately \$100 000.

But what will AIDS cost the country in the future when people in a hidden pool of at least 14 000 HIV-infected Canadians begin to develop full-blown AIDS? Not only will governments have to decide how to deal with this issue, said Royal Bank chief economist John McCallum, but also businesses will have to begin to plot strategies of their own.

McCallum delivered a stirring presentation to a blue-ribbon crowd of industry and commerce leaders during the XI International Conference on AIDS in Vancouver in July. He spoke of AIDS in terms of human capital and socio-economic costs, placing the tab for the productivity lost so far at \$8 billion. He predicts that amount will rise to \$15 billion for the estimated total of 30 000 Canadian AIDS patients expected by the turn of the century, and to \$30 billion from a cumulative total of 60 000 Canadian AIDS patients by 2010.

By adding the estimated \$100 000 in direct medical costs for each patient, he said the total cumulative cost of AIDS in Canada is \$10 billion in 1996 and could reach \$36 billion in 2010.

"Even these numbers are too

low," said McCallum, "and they should be seen as minimum estimates. The numbers take no account of direct nonmedical costs, like the cost of social assistance and for the time and care provided by friends and relatives. And they certainly say nothing about the human dimension."

The AIDS pandemic hasn't yet had a major impact on the business community, so captains of industry have had no urgent need to deal with it. McCallum talked about the disease in terms designed to convince business leaders to get involved.

"Behind these numbers, apart from the human faces, are consumer-workers in the prime of life, spending money on all sorts of goods and services, from Big Macs to cars to houses and residential mortgages," he said.

Dr. Hedy Fry, a member of Parliament in Vancouver and former president of the British Columbia Medical Association, used the meeting to unveil a new Health Canada program called the Business Case for HIV/AIDS. The program provides businesses with a how-to guide intended to encourage involvement in HIV/AIDS-related issues.

Fry spoke with emotion: "You've probably all heard this but I don't think it harms to carve it somewhere in your frontal lobes: in Canada, many people living with HIV/AIDS are full-time employees." By developing policies

and education programs for employees that focus on awareness and prevention and, in turn, eliminate fear and prejudice, businesses can make a truly significant contribution to the fight against AIDS.

"When else can business say it has an opportunity to change society, not just the bottom line?" Fry asked.

For its part, the Royal Bank contributed approximately \$500 000 to AIDS research and education programs in 1995, said McCallum. The bank earned a net profit of \$1.2 billion that year and gave \$15 million to charitable groups and agencies.

"A half-million dollars is quite significant," McCallum told CMAJ following his speech. "I think we've done something significant already. Whether we'll do more in the future, I don't know."

Small companies can and should contribute too, he said. "I'm not suggesting they can contribute as much as the Royal Bank but corporations can get their own houses in order in terms of their policies towards their own employees.

"Even if it's not a question of money, corporate leaders can speak out in terms of supporting the fight against AIDS, giving something themselves, being positive about government support, and talking about taxes and other bottom-line implications AIDS holds for Canadians. That is a contribution as well."



Rick Chalifoux: conference an enormous help

bemoaned the snail's-pace approval process for new drugs and decried the federal government's failure to develop a replacement for the National AIDS Strategy.

"I'm going to go back to Toronto and I'm going to be unable to practise at the current standard of care because these [new] drugs are unavailable to my patients. They will be asking to purchase it and I will not be able to give it to them because the drugs have not been approved.

"To have an international conference in Vancouver with the Canadian government running in nearly last place in terms of progress is an embarrassment to me as a Canadian citizen and as an AIDS physician."

One participant asked Third World delegates if they felt AIDS patients in North America should simply be happy with what they've

got. Ken Chaplin, a Toronto AIDS patient, said the answers were intriguing. "These Africans look at me

information and inspiration to spread his message of awareness and prevention in his hometown of St.

Durex bought Official Condom status for the conference, prompting cynics to wonder which firm had purchased Official Syringe rights.

and say, 'Wow! He's got it all,' but from my own eyes I don't. But they don't seem to begrudge us asking for more. They said 'keep fighting.' Yet people in the Third World can only expect minimal painkillers and that's it — no treatment, just someone to hold you down as you die."

The gap in resources, even in the developed world, was most apparent at a trade-fair style exhibit floor dominated by drug companies that had set up townhouse-sized, two-storey booths. Durex bought Official Condom status for the conference, prompting cynics to wonder which firm had purchased Official Syringe rights. Booths occupied by nonprofit, educational and support groups resembled the cheap, ramshackle digs seen at psychic fairs. Activists staged regular uprisings, storming drug-company stalls, humiliating the people working there and plastering their booths with "AIDS Profiteer" stickers.

Rick Chalifoux, an AIDS educator, understands the politics but works for change at his own pace. He said the conference was an enormous help. It armed him with new

Albert, an Edmonton suburb.

Chalifoux was cowlinner of Citizen of the Year honours in St. Albert last year for his work educating teens about HIV and AIDS. His father is an alderman and vice-principal at the local Catholic high school. His mother is active in the city's volunteer movement and the family, overall, has a high profile. The students Chalifoux talks to in the small, upscale community are more likely to use a syringe to take steroids at some health club than to inject street drugs in a back-alley shooting galleries, but he and Gloria Powder share the same concerns in different worlds: with or without the conference, both are stuck fighting a disease that is 100% preventable but is making frightening inroads. Yet for everything the two AIDS educators have in common, there's an enormous difference: one of them is dying of AIDS.

"That's the thing about HIV, you can't tell who's carrying it," Powder reflected. "I know how lucky I am."

[Editor's note: Rick Chalifoux died Sept. 24 as this article was going to press.]■